

**Joe Brown**  
**Parkinson's Action Network State Coordinator, Texas**  
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Thank you, Mr. Chairman and members of the subcommittee for inviting me today. My name is Joe Brown. I am a state coordinator for the Parkinson's Action Network, a founding member and vice-president of Texans for the Advancement of Medical Research and a founding member of The Alliance for Medical Research. I have been an advocate for twenty years.

As someone living with chronic disease, as a patient and active caregiver, I was dismayed when I read the memorandum published by the Committee that appeared to reach pertinent conclusions before this hearing even convened. It mistakenly concluded that Somatic Cell Nuclear Transfer (SCNT) is not supported by current science and that those who support this research have created an "unjustified hype" that plays on the hopes of suffering patients.

I'm not going to talk about theory or intellectual concepts; I'm going to talk about life - my life, my wife's life and the lives of you and your family.

Having watched a genetic form of Parkinson's slowly steal the quality of life from my beautiful wife, I'm concerned for my children and grandchildren.

I have lived 70 years with a genetic heart condition that has sudden death as its most significant side effect. Having been fortunate enough to survive 3 heart attacks, bypass surgery, cardiac arrest and cancer, I have reason to "hope"—especially since I have benefited from research that was thought to be wrong and unethical. I was the ninth person in the United States to have a procedure that took me from being unable to walk from one room to another and with days filled with countless hours of angina, to being able to carry my grandchild up a flight of stairs.

This procedure, which actually gives the patient a heart attack to reduce obstructive heart muscle, was originated by a Swiss cardiologist. Switzerland didn't believe that giving heart attacks was ethical and wouldn't allow the procedure. The quality of my life was improved because Dr. Sigwart was forced to leave his country, just as American scientists are doing today in order to pursue stem cell research.

So, yes, as a patient, I do have hope that SCNT will succeed. But it is not "unjustified" hope. The breakthroughs have been exciting and amazing, but I recognize that sound research takes time. It took 52 years for the polio vaccine to get to market. I don't expect the scientific community to have these treatments or cures available in my lifetime, but if we don't start now the cures won't be there for our children and grandchildren.

When I visited the University of Texas Medical Branch in Galveston, scientists working with adult stem cells told me that the most significant advances in adult stem cell research have occurred since embryonic stem cells were first isolated in 1998. The reason the

scientists gave me is that the embryonic stem cells are teaching them how to work with adult stem cells. To promote one form of stem cell research to the exclusion of another is counterproductive.

I am astounded that there are those who don't recognize, that while there may be fraudulent researchers, by definition, it is impossible for research in and of itself, to be fraudulent.

We don't stop basketball games when a player is called on a foul, nor do we stop having congressional sessions due to a Representative's misconduct. In the future, as in the past, scientific fraud will be detected when peers are unable to replicate the results. Unfortunately this self-policing mechanism has been disengaged in our country because the federal government isn't supporting the research.

The fact that one scientist apparently procured egg donations without appropriate attention to the welfare of the patients doesn't mean that everyone else will do the same. Women have a right to donate eggs for the benefit of others.

It is incumbent upon the United States, where both quality of science and dignity of life are of uppermost concern, to take the lead in creating an appropriate framework for stem cell research, while promoting and protecting its progress.

On behalf of my family and the more than one million of Americans with Parkinson's disease who would benefit from this research moving forward, I appreciate the opportunity to provide testimony to the Subcommittee today.